Counting and Caring for Chronically Ill Children: The Need for a Paediatric Registry

Abstract:

The recent H1N1 influenza pandemic exposed a reparable medical conundrum. The National Immunization Advisory Committee and National Immunization Office were asked to prioritize susceptible groups of children for early immunization with initial limited supplies of H1N1 vaccines. Unfortunately, no national database or numerical denominator was available. The groups of children identified as at high risk of H1N1 complications included those with chronic respiratory disease (especially cystic fibrosis), chronic heart disease, chronic renal disease, chronic neurological disease, immunosuppression, haemoglobinopathies, diabetes mellitus, significant physical or intellectual disability (including Down Syndrome, cerebral palsy, muscular dystrophy). All of these children attended family doctors and children’s units / hospitals, many were in receipt of long term illness drug schemes, and some were on the list requiring high-tech expensive medications. Yet there was no national data-base to identify or numerate them. It is hard to believe that Ireland does not have a valid reliable current head count of the number of children with cystic fibrosis or diabetes mellitus, for example.

Every paediatric specialty has its collection of chronically ill children who will require indefinite long term care, expensive medications, costly appliances, sophisticated technology (automated peritoneal dialysis, home respirators, etc). Yet no one seems to know who they are, where they are and how to access them. Ireland needs a paediatric registry to count such children on an annual basis, with a view to establishing a data base, thus enabling the HSE to do organised forward planning and cost analyses for equipment, staff, community and hospital facilities.

The Table, which is neither exclusive or all inclusive, lists some conditions that should be collected annually on a prospective basis. In a previous editorial for this journal (IMJ, January 2009), I estimated (for lack of data) that there were in Ireland: 1800 children with inborn errors of metabolism; 600-800 children with cystic fibrosis; 2500-3000 children with diabetes mellitus; 1500-2000 children with Down Syndrome. But this is simply not good enough. The nation and its children need an accurate head count. A registry has worked well for counting cancer sufferers; it would work equally well for chronically ill children. The National Cancer Registry established in 1991 has done an exemplary job. Eurocat is based in Ulster. Ireland needs to carefully count and care for those children who will need chronic treatment, support and services.

The Children’s University Hospital, Temple Street which houses the National Newborn Screening programme, the Sudden Infant Death Registry and the Irish Paediatric Surveillance Unit, is in a unique position to establish and manage a national Paediatric Registry. Hopefully the HSE can see the need and wisdom for such a registry and can provide appropriate funding to establish and run it. It should not cost too much. Medical epidemiology and proper planning are data based.

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Comments: